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Open Diary

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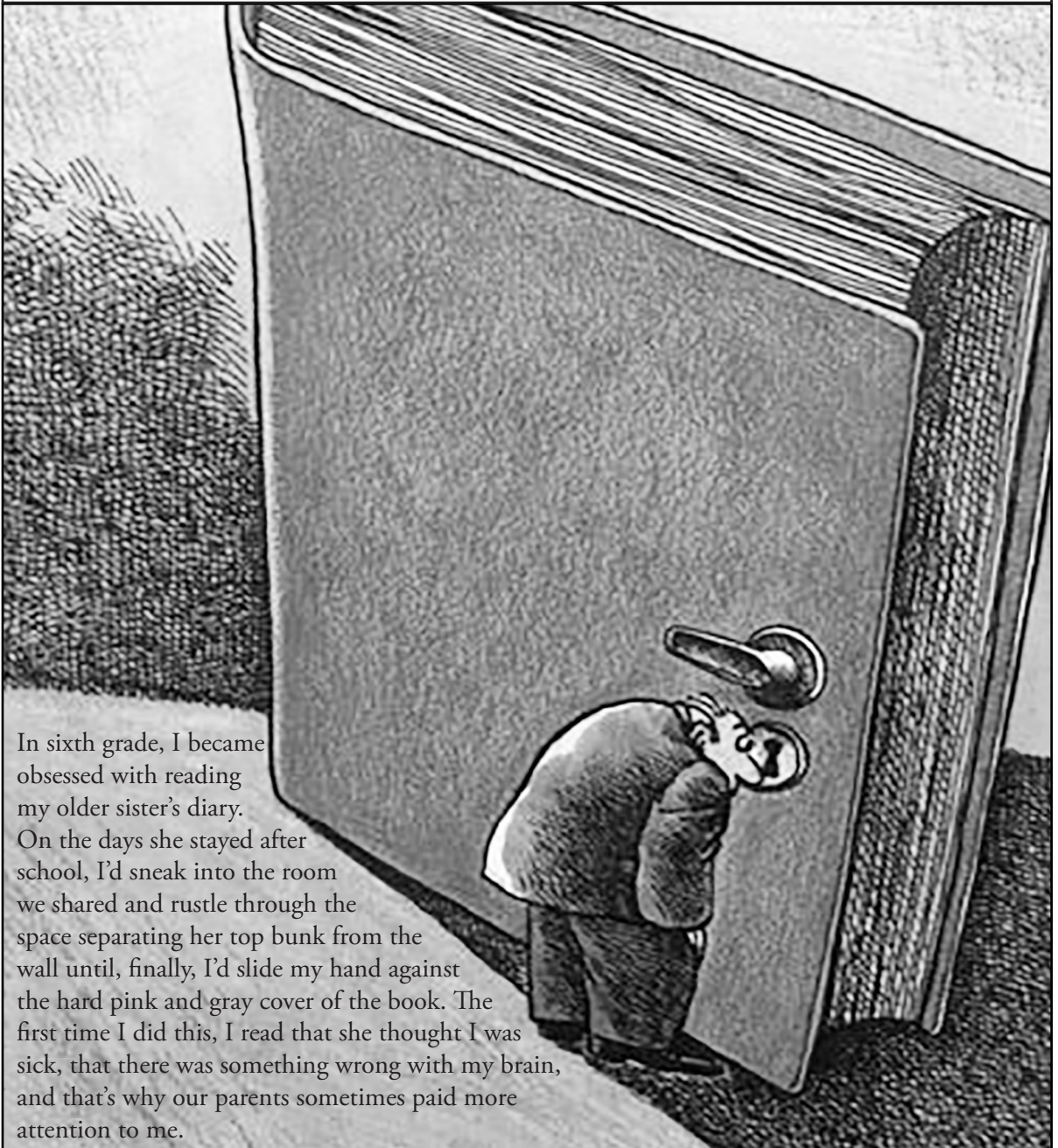
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KATHRYN WARING

Open Diary

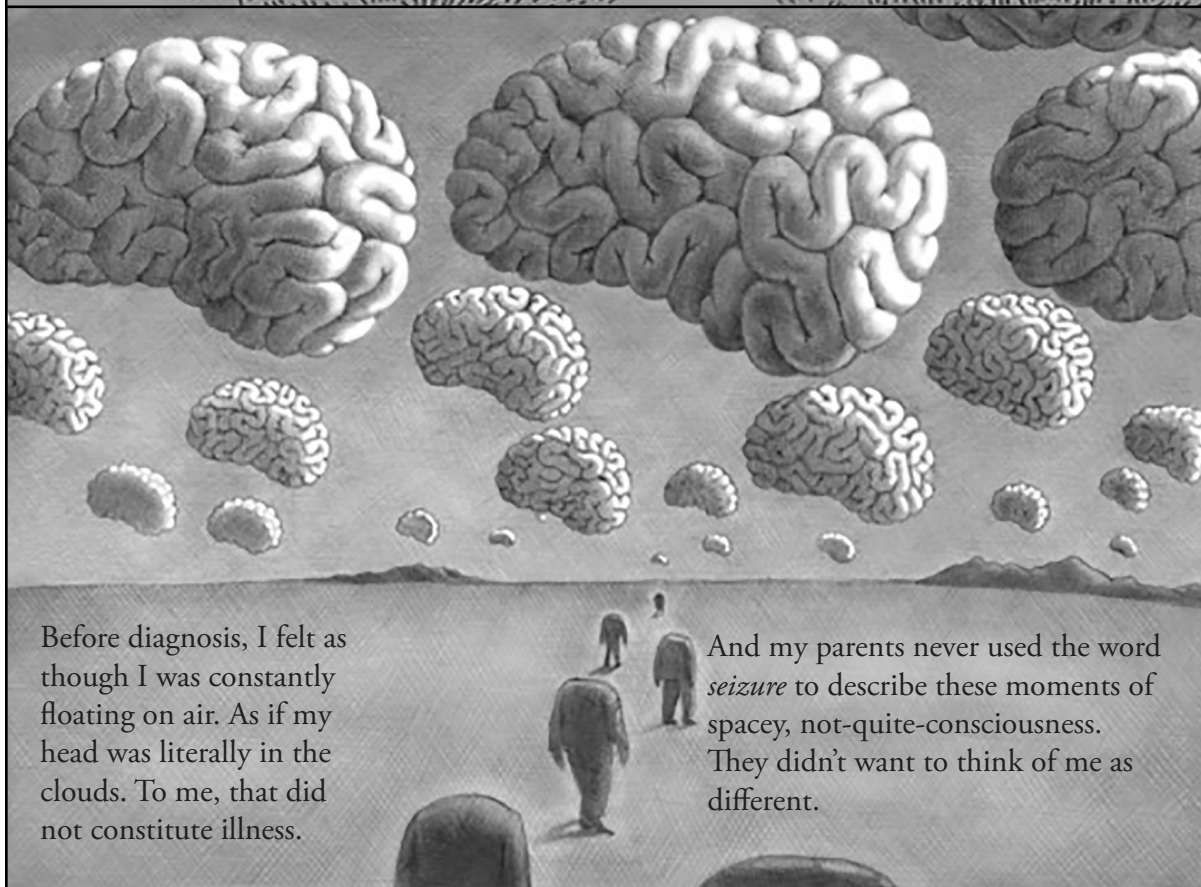


In sixth grade, I became obsessed with reading my older sister's diary. On the days she stayed after school, I'd sneak into the room we shared and rustle through the space separating her top bunk from the wall until, finally, I'd slide my hand against the hard pink and gray cover of the book. The first time I did this, I read that she thought I was sick, that there was something wrong with my brain, and that's why our parents sometimes paid more attention to me.

Although I was seven when
I was diagnosed
with epilepsy,
I'd never
thought
of
myself
as sick.

I was not sick.

"Sick" was a
word I equated
with dying,
with hospitals,
with people
who had cancer
or a disease
with a name I
was unable to
pronounce.



Before diagnosis, I felt as
though I was constantly
floating on air. As if my
head was literally in the
clouds. To me, that did
not constitute illness.

And my parents never used the word
seizure to describe these moments of
spacey, not-quite-consciousness.
They didn't want to think of me as
different.

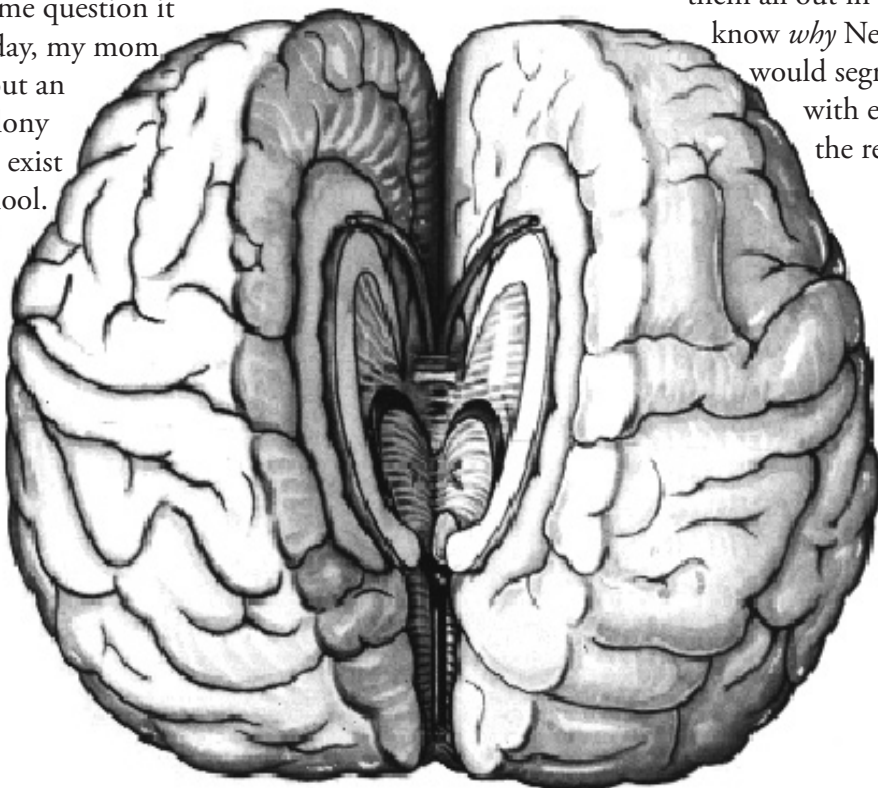
So when my sister said I was sick, I kept reading. Every chance I got, I would sneak into our room and find her diary. So that there would be no secrets.



Nothing hidden.

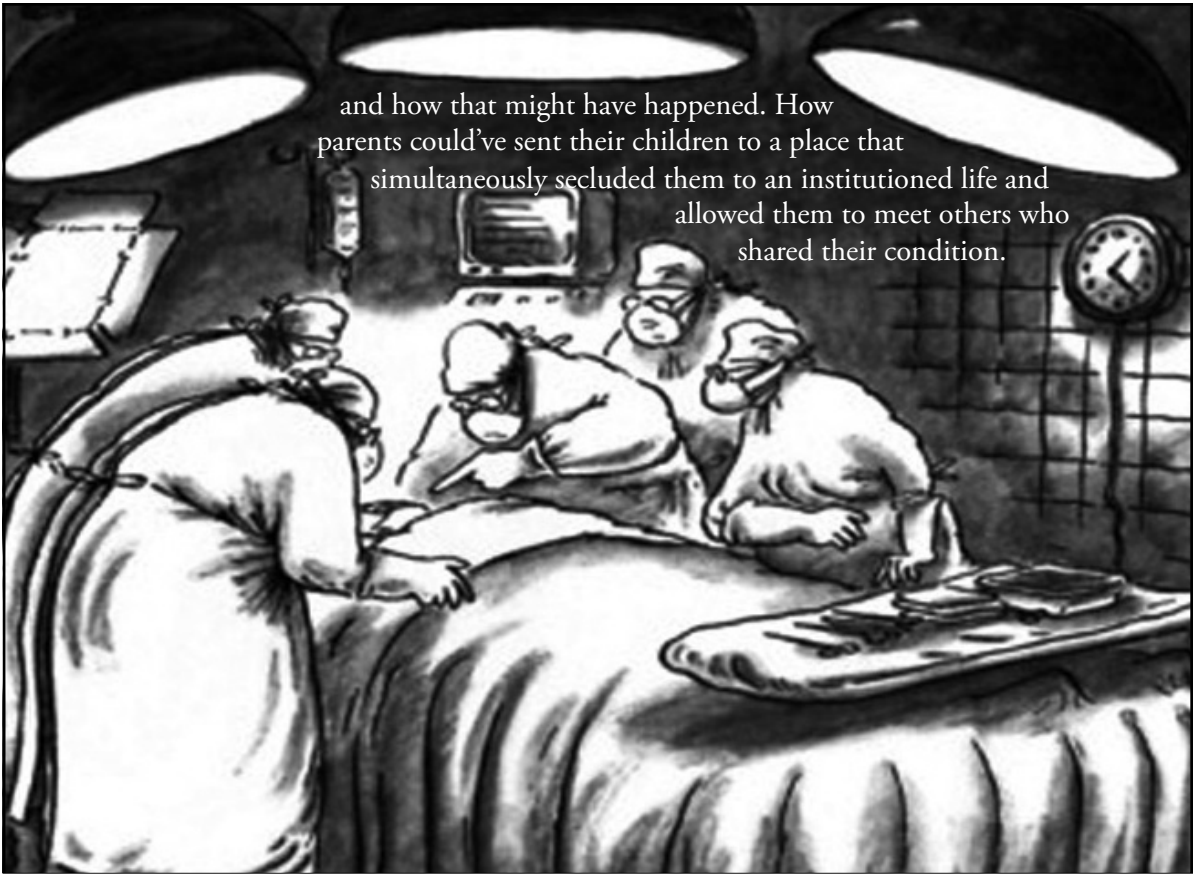
I wanted to be as open as possible.

And perhaps that openness is what made me question it when, one day, my mom told me about an epileptic colony that used to exist near my school.



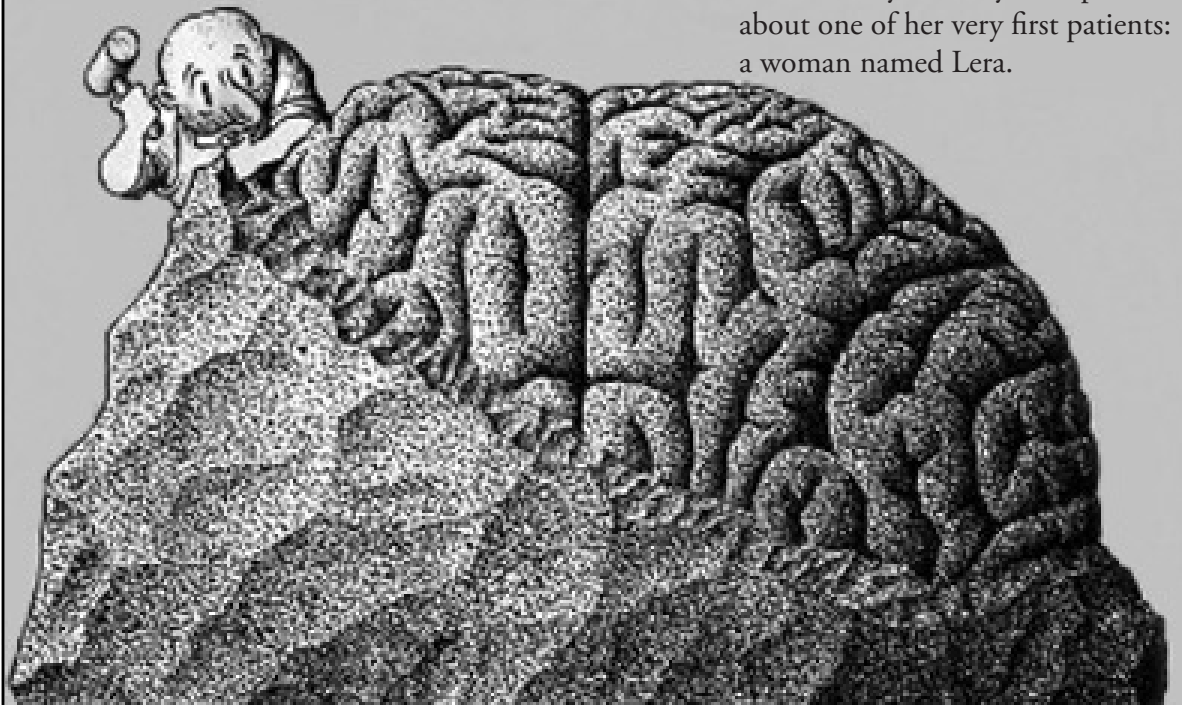
I needed to know the facts, to have them all out in the open. To know *why* New York State would segregate people with epilepsy from the rest of society,

and how that might have happened. How parents could've sent their children to a place that simultaneously secluded them to an institutioned life and allowed them to meet others who shared their condition.



So I found a nurse who used to work at the colony and interviewed her.

And although she couldn't tell me much about the whys or hows of the colony's history, she spoke about one of her very first patients: a woman named Lera.



Lera's husband admitted her to Craig Colony after she developed a seizure disorder, the result of a tumor in her brain.

The doctors at the colony thought relieving some of the pressure would rid her of the seizures, so they removed the top of her skull.

When the nurse started at the colony a decade later, she noticed Lera had a dip in her skull that was so soft, she could feel the brain.

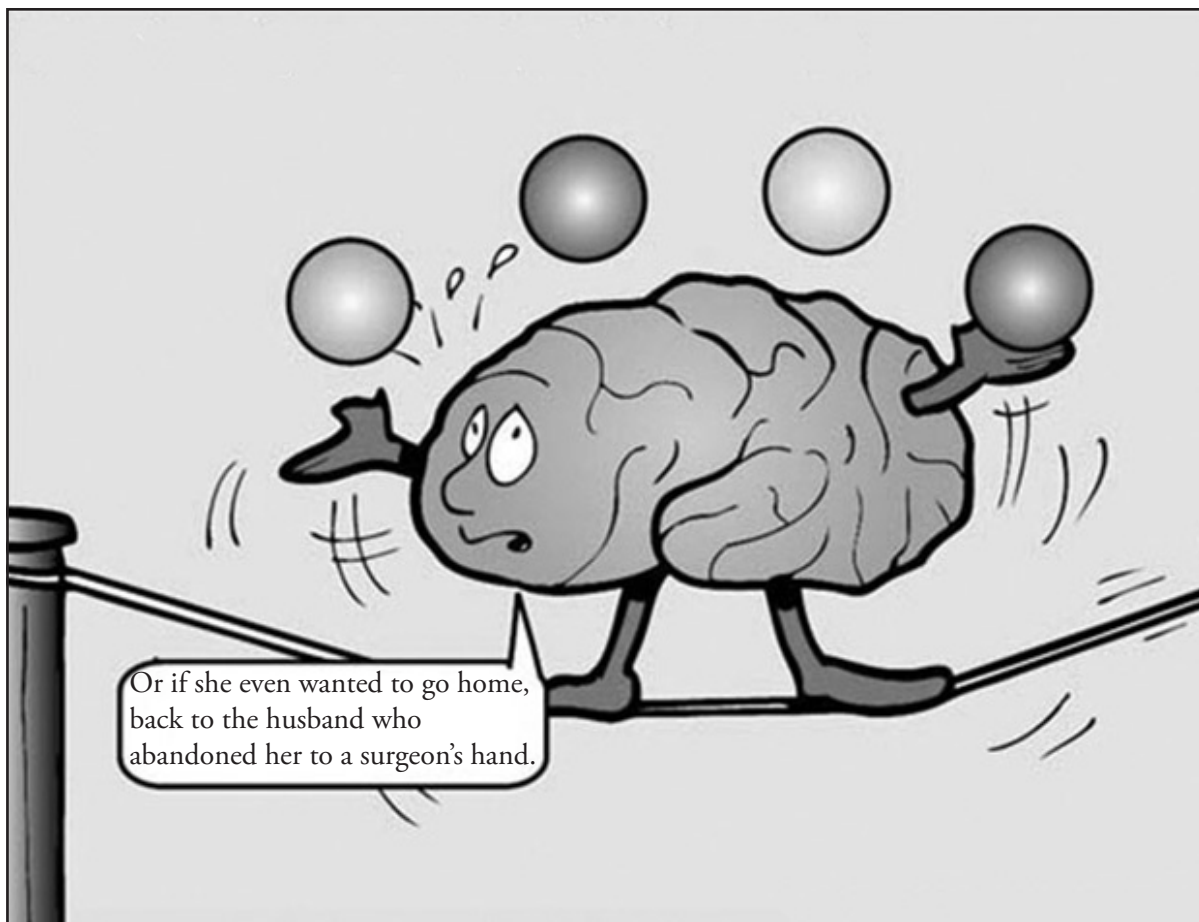


And I wondered:

If it was just chance that the doctors prevented her skull from cracking like an egg.

If knife scraped against bone when it began.

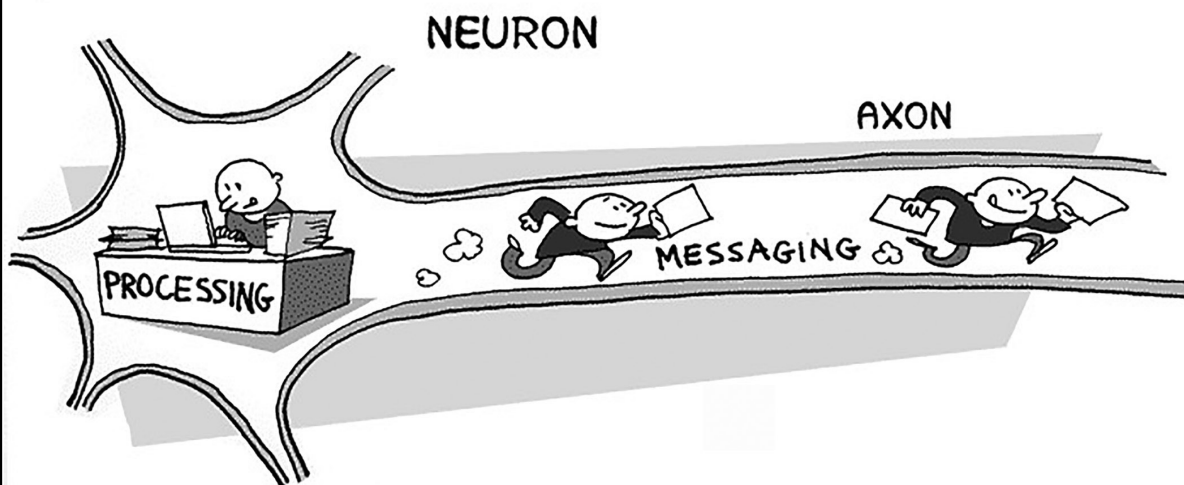




And even though I was never subject
to surgery like Lera,

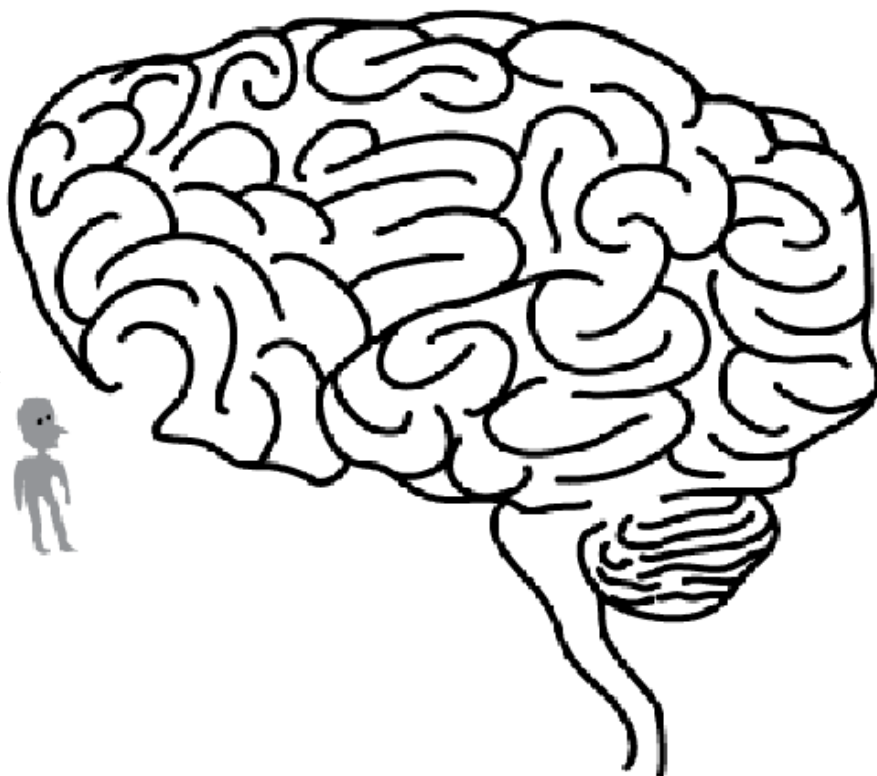


I felt like I could relate to her
on some small level



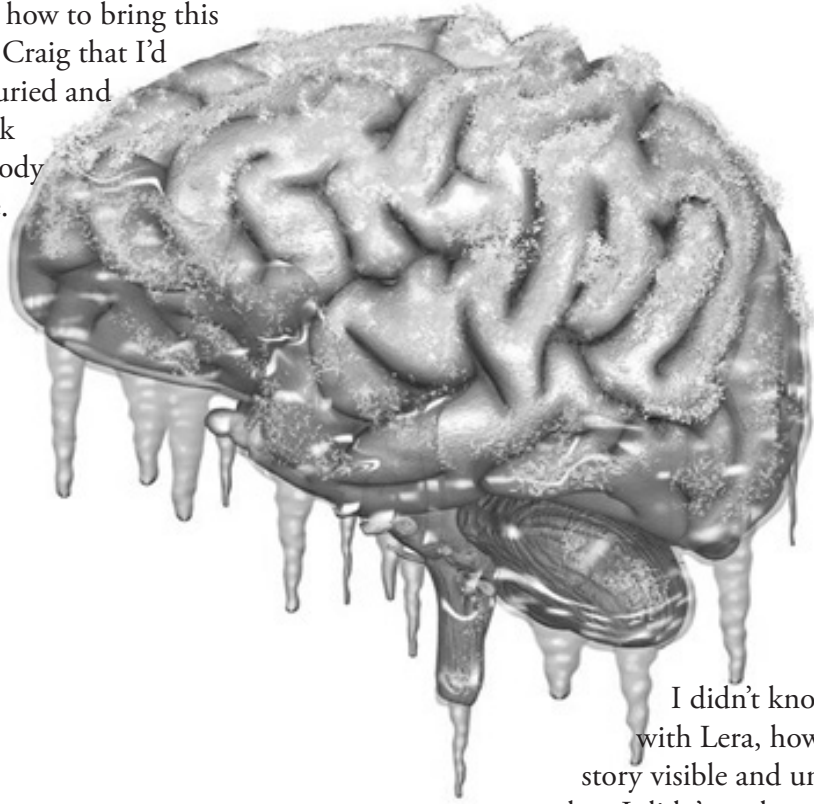
because we both had bodies
operating outside our control.

So I kept searching.
And though I didn't
find anything else
about Lera, I
learned that Craig
Colony opened in
1896, that it stayed
open through the
1980s, that it had
a history steeped
in Nazi policy and
American eugenics.

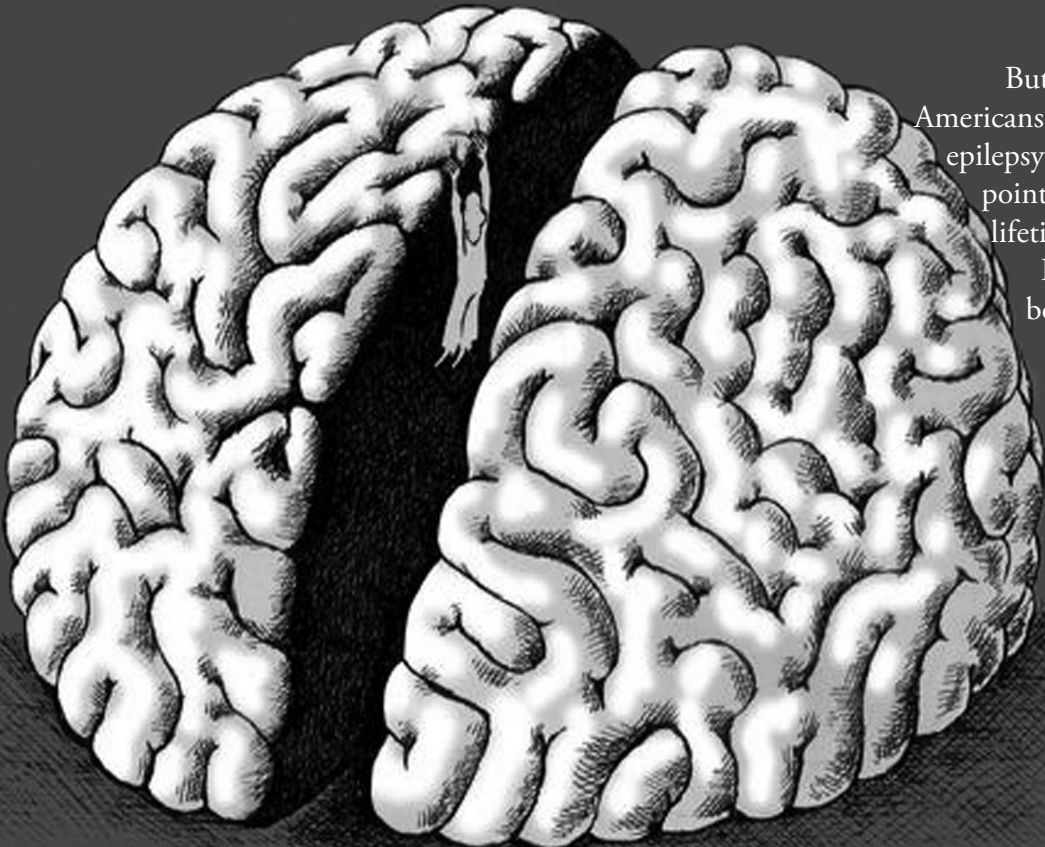


And I realized: if I'd been born a few decades earlier,
I could've ended up in Craig.

And I didn't know what to do with this knowledge, how to bring this information on Craig that I'd absorbed and buried and internalized back outside of my body for others to see.



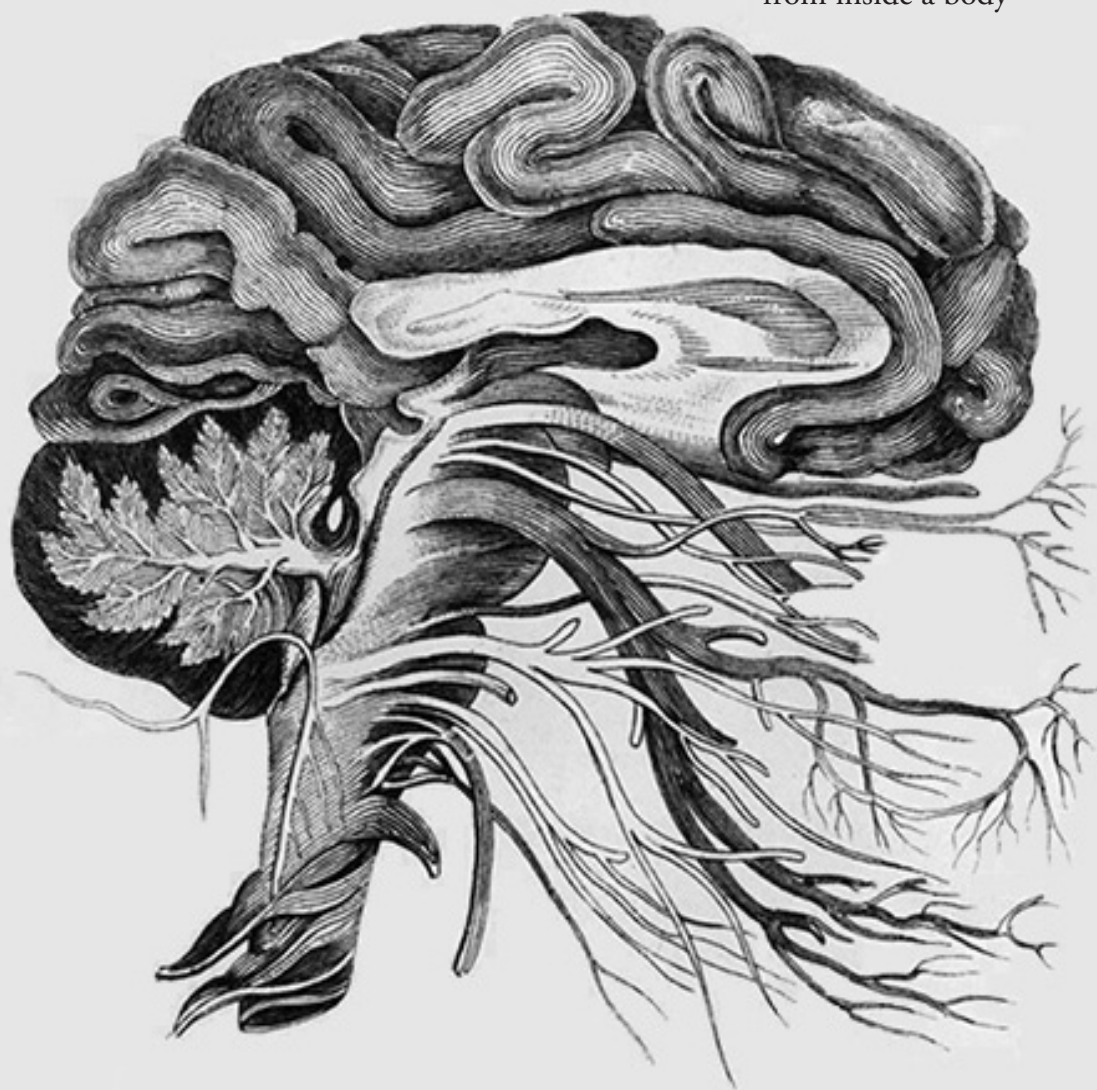
I didn't know what to do with Lera, how to make her story visible and understandable when I didn't understand it myself.



But 1 in 26 Americans develop epilepsy at some point in their lifetime, and Lera was born only decades before you and me

and we are all forced to experience life

from inside a body



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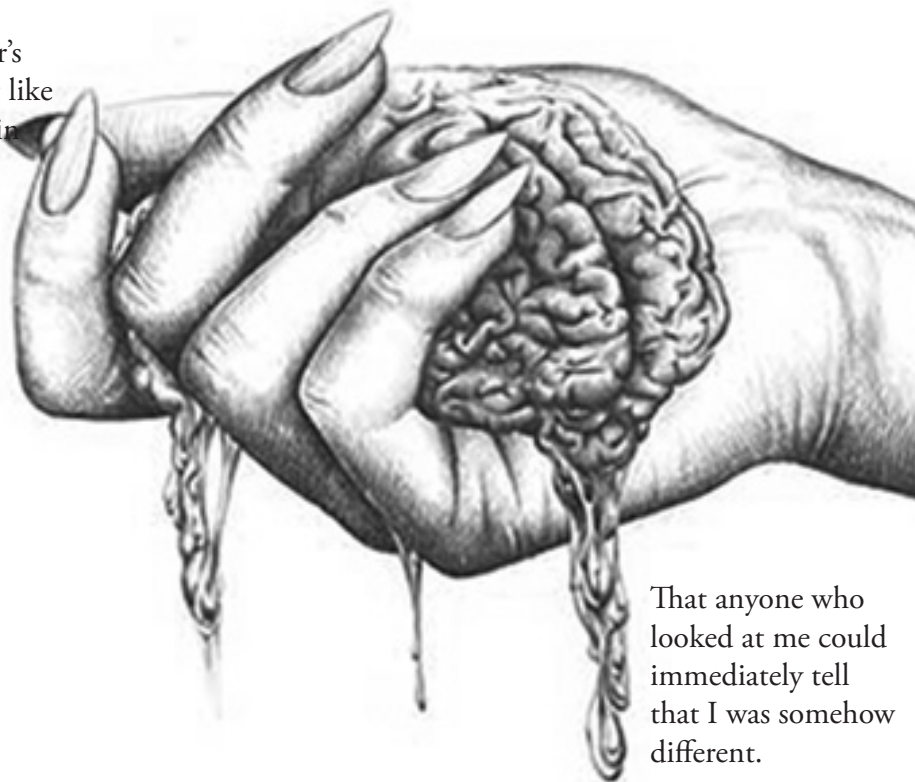
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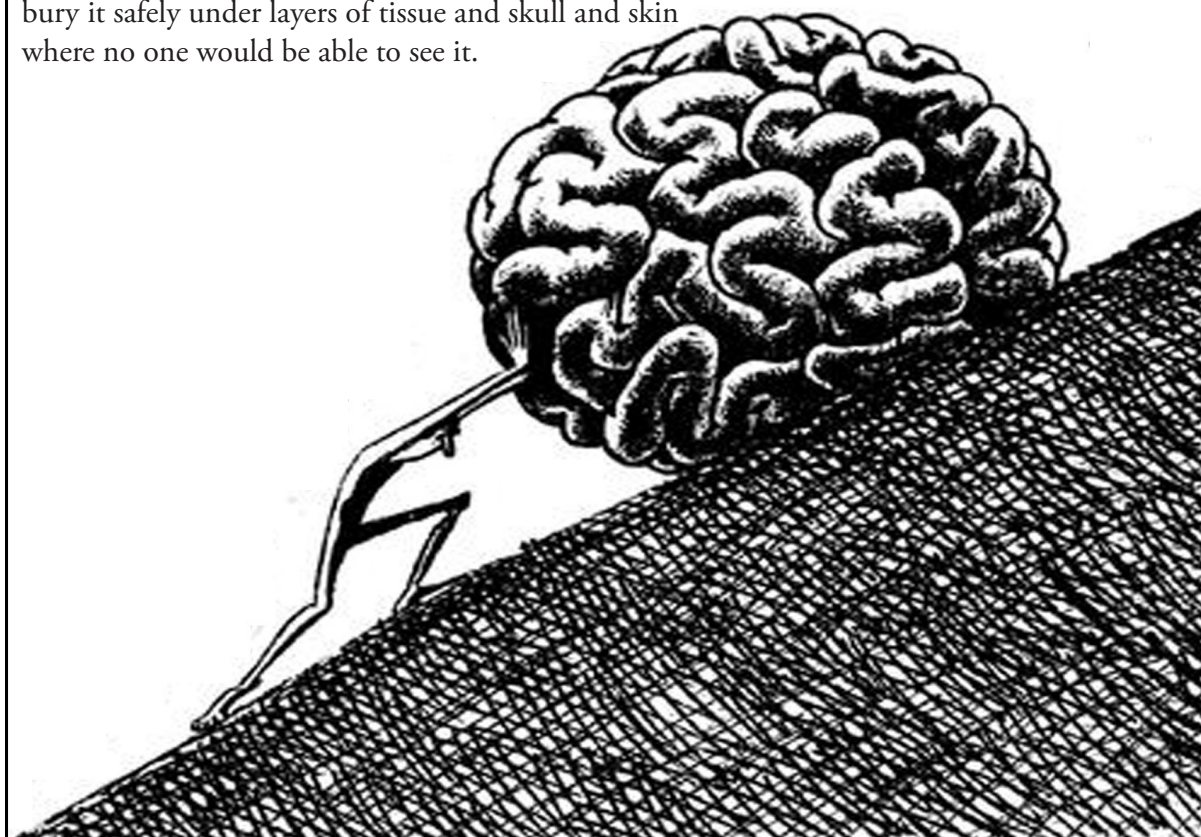
suddenly, and without
explanation.

After reading my sister's diary, I sometimes felt like I was carrying my brain around in my hand.

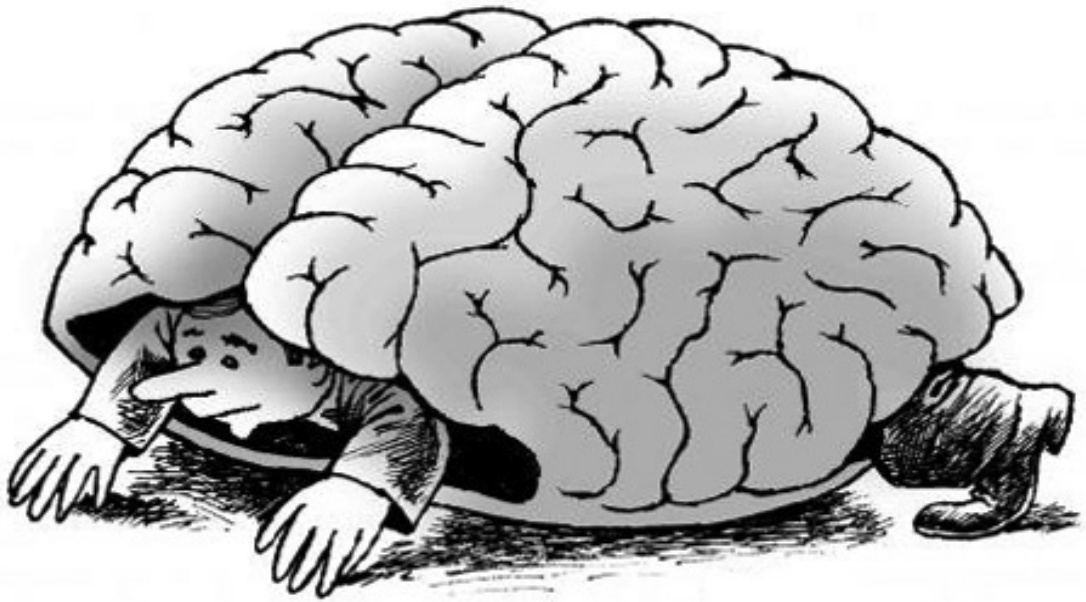


That anyone who looked at me could immediately tell that I was somehow different.

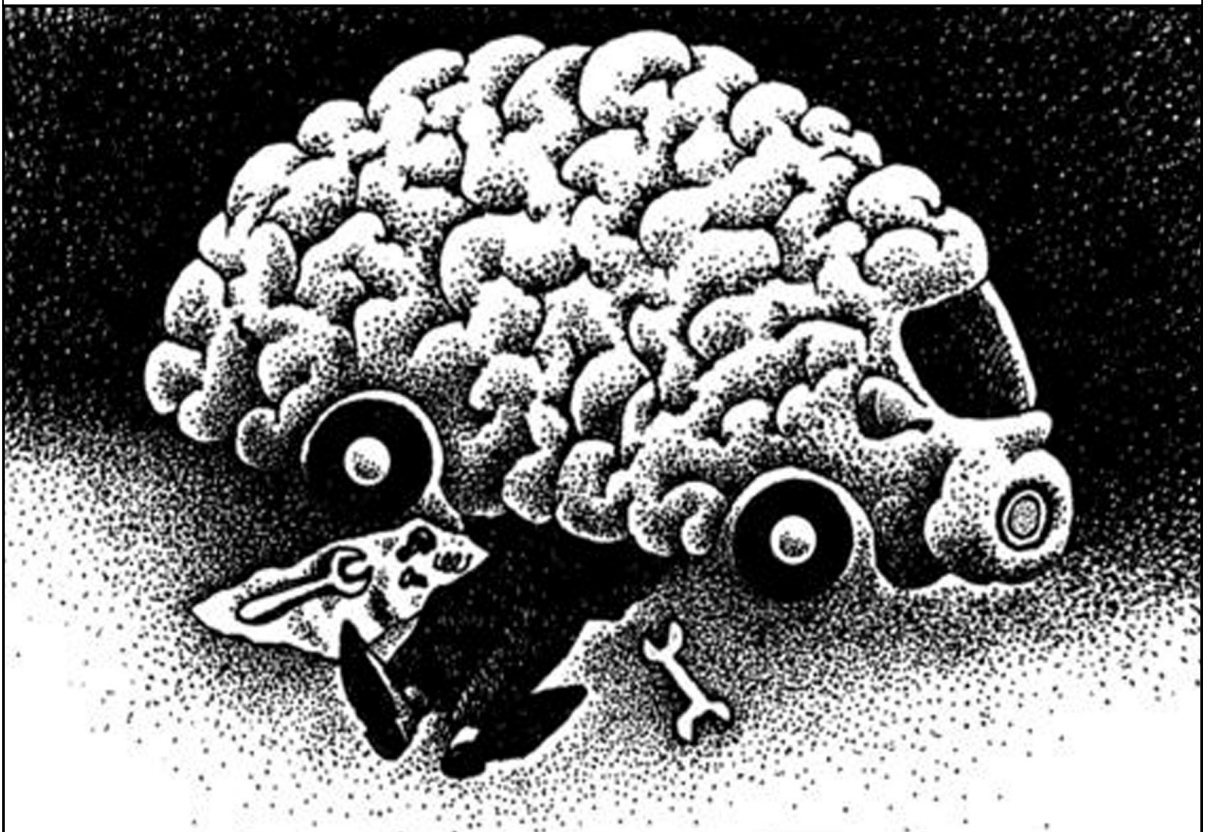
And, because of this, I wanted to pack my brain away, bury it safely under layers of tissue and skull and skin where no one would be able to see it.



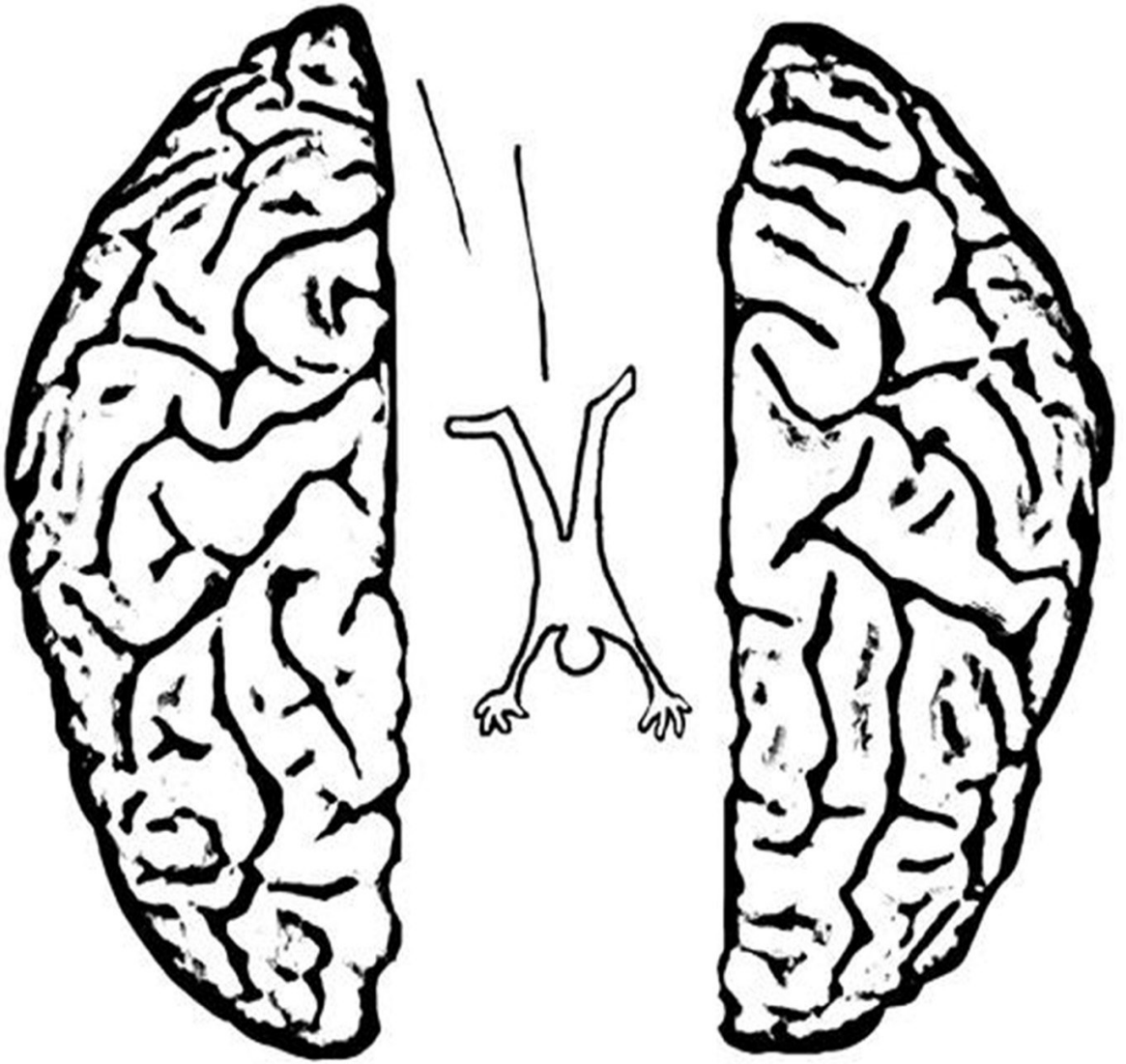
But after years of trying to hide,



I realized it's not possible to burrow
our differences away.



After all, we're all just bodies in constant states of repair



slowly opening to the world around us.